DOCUMENT RESUME

ED 370 269 EC 302 999

TITLE	Spina Bifida: General Information. Fact Sheet Number 12 = La Espina Bifida: Informacion General. Fact Sheet Number 12.
INSTITUTION	Academy for Educational Development, Inc., Washington, D.C.; National Information Center for Children and Youth with Disabilities, Washington, DC.
SPONS AGENCY	Special Education Programs (ED/OSERS), Washington, DC.
PUB DATE	Mar 94
CONTRACT	H030A30003
NOTE	5p.; For a previous edition, see ED 353 712. Fact Sheet regularly updated. For later updates, contact NICHCY.
AVAILABLE FROM	National Information Center for Children and Youth with Disabilities (NICHCY), P.O. Box 1492, Washington, DC 20013-1492.
PUB TYPE	Information Analyses (070) -- Multilingual/Bilingual Materials (171)
LANGUAGE	English; Spanish
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	Definitions; *Educational Methods; Elementary Secondary Education; Incidence; Individual Characteristics; *Spina Bifida; *Symptoms (Individual Disorders)

ABSTRACT

This fact sheet offers definitions of the three types of spina bifida, outlines their incidence, describes characteristics of individuals with spina bifida, and reviews educational implications. The fact sheet emphasizes that school programs should be flexible to accommodate these students' special needs and frequent absences, that children with spina bifida and a history of hydrocephalus often experience learning problems, that mainstreaming sometimes requires changes in school equipment or curriculum, and that children with spina bifida should be encouraged to be independent and to participate in activities with nondisabled classmates within the limits of safety and health. A list of three print resources and five organizations is provided. (JDD)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

Fact Sheet Number 12 (FS12), 1993

ED 370 269

NICHCY

National Information Center for Children and Youth with Disabilities
P.O. Box 1492, Washington, D.C. 20013-1492
1-800-695-0285 (Toll Free, Voice/TT)
*SpecialNet User Name: NICHCY ** SCAN User Name: NICHCY*

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

General Information About

SPINA BIFIDA

Definition

Spina Bifida means cleft spine, which is an incomplete closure in the spinal column. In general, the three types of spina bifida (from mild to severe) are:

1. **Spina Bifida Occulta:** There is an opening in one or more of the vertebrae (bones) of the spinal column without apparent damage to the spinal cord.

2. **Meningocele:** The meninges, or protective covering around the spinal cord, has pushed out through the opening in the vertebrae in a sac called the "meningocele." However, the spinal cord remains intact. This form can be repaired with little or no damage to the nerve pathways.

3. **Myelomeningocele:** This is the most severe form of spina bifida, in which a portion of the spinal cord itself protrudes through the back. In some cases, sacs are covered with skin; in others, tissue and nerves are exposed. Generally, people use the terms "spina bifida" and "myelomeningocele" interchangeably.

Incidence

Approximately 40% of all Americans may have spina bifida occulta, but because they experience little or no symptoms, very few of them ever know that they have it. The other two types of spina bifida, meningocele and myelomeningocele, are known collectively as "spina bifida manifesta," and occur in approximately one out of every thousand births. Of these infants born with "spina bifida manifesta," about 4% have the meningocele form, while about 96% have myelomeningocele form.

Characteristics

The effects of myelomeningocele, the most serious form of spina bifida, may include muscle weakness or paralysis below the area of the spine where the incomplete closure (or cleft) occurs, loss of sensation below the cleft, and loss of bowel and bladder control. In addition, fluid may build up and cause an accumulation of fluid in the brain (a condition known as hydrocephalus). A large percentage (70%-90%) of children born with myelomeningocele have hydrocephalus. Hydrocephalus is controlled by a surgical procedure called "shunting," which relieves the fluid buildup in the brain. If a drain (shunt) is not implanted, the pressure buildup can cause brain damage, seizures, or blindness. Hydrocephalus may occur without spina bifida, but the two conditions often occur together.

Educational Implications

Although spina bifida is relatively common, until recently most children born with a myelomeningocele died shortly after birth. Now that surgery to drain spinal fluid and protect children against hydrocephalus can be performed in the first 48 hours of life, children with myelomeningocele are much more likely to live. Quite often, however, they must have a series of operations throughout their childhood. School programs should be flexible to accommodate these special needs.

Many children with myelomeningocele need training to learn to manage their bowel and bladder functions. Some require catheterization, or the insertion of a tube to permit passage of urine.

The courts have held that clean, intermittent catheterization is necessary to help the child benefit from and have access to special education and related services. A successful bladder management program can be incorporated into the regular school day. Many children learn to catheterize themselves at a very early age.

In some cases, children with spina bifida who also have a history of hydrocephalus experience learning problems. They may have difficulty with paying attention, expressing or understanding language, and grasping reading and math. Early intervention with children who experience learning problems can help considerably to prepare them for school.

EC 302999

Mainstreaming, or successful integration of a child with spina bifida into a school attended by nondisabled young people, sometimes requires changes in school equipment or the curriculum. Although student placement should be in the least restrictive environment the day-to-day school pattern also should be as "normal" as possible. In adapting the school setting for the child with spina bifida, architectural factors should be considered. Section 504 of the Rehabilitation Act of 1973 requires that programs receiving federal funds make their facilities accessible. This can occur through structural changes (for example, adding elevators or ramps) or through schedule or location changes (for example, offering a course on the ground floor).

Children with myelomeningocele need to learn mobility skills, and often require the aid of crutches, braces, or wheelchairs. It is important that all members of the school team and the parents understand the child's physical capabilities and limitations. Physical disabilities like spina bifida can have profound effects on a child's emotional and social development. To promote personal growth, families and teachers should encourage children, within the limits of safety and health, to be independent and to participate in activities with their nondisabled classmates.

Resources

Bloom, B.A., & Seljeskog, E.S. (1988). *A parent's guide to spina bifida*. Minneapolis, MN: University of Minnesota Press. (Telephone: 1-800-388-3863.)

National Institute of Neurological and Communicative Disorders and Stroke. (1986). *Spina bifida: Hope through research*. (Available from the Spina Bifida Association of America. See address under organizations.)

Williamson, G. (Ed.). (1987). *Children with spina bifida: Early intervention and preschool programming*. Baltimore: Paul H. Brookes. (Available from Paul H. Brookes Publishing Co. at 1-800-638-3775.)

Organizations

Spina Bifida Association of America
4590 MacArthur Boulevard, Suite 250
Washington, D.C. 20007
(202) 944-3285
(1-800) 621-3141 (Toll Free)

March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue
White Plains, NY 10605
(914) 428-7100

National Center for Education in Maternal and Child Health
8201 Greensboro Dr., Suite 600
McLean, VA 22102
(703) 821-8955, Ext. 254 or 265

National Easter Seal Society
230 West Monroe Street, Suite 1800
Chicago, IL 60606
(312) 726-6200
(1-800) 221-6827 (Toll Free)

National Rehabilitation Information Center (NARIC)
8455 Colesville Road, Suite 935
Silver Spring, MD 20910-3319
(301) 588-9284
(1-800) 227-0216 (Toll Free)

This fact sheet is made possible through Cooperative Agreement #H030A30003 between the Academy for Educational Development and the Office of Special Education Programs, U.S. Department of Education. The contents of this publication do not necessarily reflect the views or policies of the Department of Education, nor does mention of trade names, commercial products or organizations imply endorsement by the U. S. Government.

This information is copyright free. Readers are encouraged to copy and share it, but please credit the National Information Center for Children and Youth with Disabilities (NICHCY).

NICHCY

National Information Center for Children and Youth with Disabilities
P.O. Box 1492, Washington, D.C. 20013-1492
1-800-695-0285 (Toll Free, Voice/TT)
*SpecialNet User Name: NICHCY ** SCAN User Name: NICHCY*

Información General Sobre

LA ESPINA BIFIDA

Definición

Espina Bifida quiere decir una partidura en la espina, o sea que la columna vertebral no se ha cerrado completamente. Hay tres tipos de espina bifida (varían de leve a severo) y éstos son:

1. Espina Bifida Oculta: Una apertura en una o más de las vértebras (huesos) de la columna espinal, sin ningún daño aparente a la médula espinal.

2. Meningocele: Los meninges (o cobertura protectiva que rodea la médula espinal) se han salido a través de una apertura en las vertebras, en un saco llamado el "meningocele."

3. Myelomeningocele: Esta es la forma más severa de espina bifida, en la cual una porción de la médula espinal sobresale a través de la espalda. En algunos casos, los sacos están cubiertos de cútis; en otros, los tejidos y nervios están expuestos. Generalmente, los términos "espina bifida" y "myelomeningocele" son usados en forma intercambiable.

Incidencia

En los Estados Unidos, aproximadamente el 40% de la población puede tener espina bifida oculta, aunque muy pocas de estas personas lo llegan a saber ya que esta condición carece de síntomas. Los otros dos tipos de espina bifida, meningocele y myelomeningocele, son conocidos como "espina bifida manifesta," y ésto ocurre en aproximadamente uno de cada 1.000 infantes. De los infantes que nacen con "espina bifida manifesta," más o menos el 4% tiene meningocele y el 96% tiene myelomeningocele.

Características

Los efectos de myelomeningocele, la forma más grave de la espina bifida, pueden incluir debilidad muscular o parálisis bajo el área donde ocurre la apertura (o hendidura), falta de sensación bajo la hendidura, e incontinencia. Existe el peligro, además, de una acumulación anormal de líquidos en el cuerpo y por lo tanto en el cerebro (resultando en una condición llamada hidrocefalía). Un gran porcentaje (70%-90%) de los niños que nacen con myelomeningocele tienen hidrocefalía. La hidrocefalía puede ocurrir sin la espina bifida, aunque frecuentemente se manifiestan juntas ambas condiciones. La hidrocefalía se controla mediante una intervención quirúrgica llamada procedimiento de derivación (shunt). Este procedimiento consiste en la introducción de una punta de un tubo flexible en un ventrículo cerebral, sacando el tubo por una pequeña apertura en el cráneo. Sin éste puede resultar una acumulación de líquidos en el cerebro, y esta presión puede causar daño cerebral, ataques, o cegüera.

Implicaciones en la Educación

Los estudiantes con espina bifida son elegibles para recibir servicios de educación especial bajo el Acta para la Educación de las Personas con Discapacidades (Ley Pública 94-142). La espina bifida se clasifica como "impedimento a la salud" (other health impaired) y la escuela y los padres tienen que desarrollar un Plan de Educación Individual (IEP) a fin de especificar los servicios apropiados.

Aunque la espina bifida es relativamente común, hasta hace poco la mayoría de los niños que nacían con myelomeningocele morían poco después de nacer. Ahora que el procedimiento de derivación para drenaje de líquido espinal puede llevarse a cabo durante las primeras 48 horas de vida, existen mayores posibilidades de que los niños con myelomeningocele puedan sobrevivir. En muchos casos, estos niños deben ser sometidos a una serie de operaciones a través de su niñez. Los programas escolares deben ser flexibles para acomodar estas necesidades especiales.

Muchos niños con myelomeningocele necesitan entrenamiento para el control de la incontinencia. Algunos requieren un catéter, o un tubo de hule o de metal que se introduce por el extremo inferior de la uretra a la vejiga, para permitir que la orina fluya libremente por el tubo y el chorro de la orina puede dirigirse a un recipiente.

El cateterismo, limpio e intermitente, es necesario para ayudar al niño a beneficiarse de y para tener acceso a la educación especial y servicios relacionados. Por lo tanto, de acuerdo a las cortes, la escuela debe proveer el cateterismo como servicio relacionado a todos los niños que lo requieren. Además, muchos niños aprenden a usar el catéter a una edad temprana.

En algunos casos, los niños con espina bifida que también tienen hidrocefalía experimentan trastornos del aprendizaje. Pueden tener dificultades con poner atención en la clase, en la comprensión o expresión, en leer, y en aritmética. Para los niños con trastornos del aprendizaje la intervención temprana les puede ayudar a prepararse para ir a la escuela.

La integración de un niño con espina bifida a la escuela con niños que no tienen discapacidades a veces requiere cambios en el ambiente colegial o al currículo. Aunque el estudiante debe colocarse en un ambiente con un mínimo de restricciones, el horario colegial también debe ser lo más normal posible. Varios factores arquitectónicos deben ser considerados antes de la adaptación del ambiente escolar. Hay que recordar que la Sección 504 del Acta de Rehabilitación de 1973 requiere que los programas que reciben fondos federales tengan accesibilidad para los niños con discapacidades. Esto puede incluir cambios estructurales (como, por ejemplo, agregar ascensores o rampas para sillas de ruedas) o mediante cambios de horario o ubicación de la sala de clases (por ejemplo, ofrecer la clase en el primer piso).

Los niños con myelomeningocele necesitan aprender destrezas de mobilidad, y frecuentemente requieren el uso de muletas, aparatos ortopédicos, o sillas de rueda. Es importante que tanto los miembros del equipo escolar como los padres comprendan las capacidades físicas del niño y sus limitaciones. Las discapacidades físicas como la espina bifida pueden tener un profundo efecto en el desarrollo socio-emocional del niño. Para promover el crecimiento personal las familias y los profesores deben alentar a los niños, dentro de los límites de la salud y bienestar, para que éstos puedan ser independientes y participar en las mismas actividades que sus compañeros sin discapacidades.

Recursos

Spina Bifida Association of America. (1984). *El niño con espina bifida.* Washington, DC: Spina Bifida Association of America. (Teléfono: (800) 621-3141.)

National Institute of Neurological and Communicative Disorders and Stroke. (1986). *Spina bifida: Hope through research.* (Ponerse en contacto con: Spina Bifida Association of America. Teléfono: (800) 621-3141.)

Organizaciones

Spina Bifida Association of America
4590 MacArthur Boulevard N.W., Suite 250
Washington, D.C. 20007
(202) 944-3285
(800) 621-3141

March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue
White Plains, NY 10605
(914) 428-7100

National Center for Education in Maternal and Child Health
8201 Greensboro Drive, Suite 600
McLean, VA 22102
(703) 821-8955, Ext. 254 o 265

National Easter Seal Society
230 West Monroe Street, Suite 1800
Chicago, IL 60606
(312) 726-6200
(800) 221-6827

National Rehabilitation Information Center (NARIC)
8455 Colesville Rd., Suite 935
Silver Spring, MD 20910-3319
(301) 588-9284
(800) 227-0216

This fact sheet is made possible through Cooperative Agreement #H030A30003 between the Academy for Educational Development and the Office of Special Education Programs. The contents of this publication do not necessarily reflect the views or policies of the Department of Education, nor does mention of trade names, commercial products or organizations imply endorsement by the U. S. Government.

This information is in the public domain unless otherwise indicated. Readers are encouraged to copy and share it, but please credit the National Information Center for Children and Youth with Disabilities (NICHCY).

BEST COPY AVAILABLE

UPDATE 3/94

For more information contact NICHCY.